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00:00.30
Leigh Ann Porter
Welcome back to the speech uncensored podcast. My name's Leigh Ann. I'm your host. I'm a speech and language pathologist in Kansas and I love talking about all the things related to our field and learning more because it is vast. It is varied. It is nuanced and it is a delight. And I'm really excited to do the One thing series where I'm interviewing SLPs in our field about the One thing they want others to know. I'm excited to be joined by Kristin Szymanek today. And she's going to be talking about the lasting effects of childhood cancer. So welcome Kristin! I'm happy to have you.

00:36.85
Kristin Szymanek
Thank you for having me I'm so excited to be a part of this really awesome series.

00:43.81
Leigh Ann Porter
Yay! All right Kristin so you're here to talk about um, childhood cancer and not just you know the facts about that and what that looks like for your particular practice, but specifically the lasting effects. And when your proposal came through I was like oh yes, like this isn't something that was on my radar but it absolutely should be. So I'm going to hand it over to you. Um, ok I like I was about to be like tell me all the things. But then I forgot. I need you to tell me a little bit more about you before we dive into our topic.

01:20.60
Kristin Szymanek
Sure. So yes, I'm Kristin Szymanek and I've been a practicing me SLP for about 10 years. I started my journey as a CF in two elementary schools. After that year I moved into an outpatient position with the pediatric hospital. Um, and for the last eight years I've been at a hospital for children with oncology and hematology diagnoses. We also serve children with other catastrophic diseases like neuromuscular disorders. I've done a little bit of PRN work in a SNF. So I've dabbled but most of my SLP career has been in medically complex peds um I have a particular interest in something that probably a lot of people haven't heard of so I'm really interested in the care of children with posterior fossa syndrome. Which is a complication that can occur after tumor resection of a brain tumor in the posterior fossa region of the brain and these patients can present with you know motor speech disorders, um dysphagia, ataxia, emotional lability and they can experience some long-term challenges which really kind of ties into what we're going to talk about today and then outside of the SLP world I like to golf, I like to

garden, I like to read a lot of audiobooks big audiobook fan. My husband and I have a wonderful dog named Louise. So yeah. That's a little bit about me.

02:54.38
Leigh Ann Porter
Oh that's awesome. Um, what's your favorite genre for your audio books? Like, what do you… do you lean towards 1 thing or do you just like whatever sounds interesting?

02:59.40
Kristin Szymanek
Um I read so I'm in an administrative role now. So I read a lot of like leadership books and books that can help me, you know, develop my team but I really lean towards. Like serial killer murder mystery type stuff. So the really dark Twisty. Yeah.

03:22.86
Leigh Ann Porter
I Love that. That's so spooky. I like some of those shows on Tv, like the detective like dark and spooky ones. Um what like for reading I'm all about light and fluffy and um.

03:31.69
Kristin Szymanek
Yeah.

03:39.43
Leigh Ann Porter
Really otherworldly. So like sci-fi and fantasy are my jam when I sit down and read because I want to be like transported to a completely different reality.

03:44.99
Kristin Szymanek
So I have to balance out sometimes with something a little bit lighter because some of these books get really heavy and I'm like oh my gosh just give me like a beach read So a little bit of everything. But yeah I lean towards some of the horror type things I suppose.

04:04.87
Leigh Ann Porter
That's awesome, that cracks me up. Okay, all right Kristin so lay it out for me. What are the facts about childhood cancer? Where can we start off people like me who have very little knowledge base in this area?

04:15.48
Kristin Szymanek
Yeah, so let's maybe let's start a little bit with some of the statistics which aren't necessarily fun but they're kind of important. So when we talk about childhood cancers um, the most common

childhood cancers are leukemias followed by brain and other central nervous system tumors and then lymphomas. So those are the ones you're going to see the most. In the United States there's about 15,000 children and that's anyone between 19 years of age. So about 15,000 um, children being diagnosed in the US each year and that number's about 400,000 worldwide so childhood cancer is rare. But fortunately as time has gone on and improvements in medicine have been made survivorship is not rare. Which is great so we are approaching somewhere around half a million childhood cancer survivors in the United States um and we expect this number to continue continue to grow as we continue to see advancements in the medical field. So that's advancements in um, the ability to diagnose patients both in both in the United States and worldwide. What we see worldwide is that sometimes these patients are passing before we're able to diagnose them or we diagnose them so late in the game that we're unable to help them at that point. So we're we're working on advancing. You know, global diagnosis of childhood cancer. Surgical techniques are improving so we're getting better at the surgeries that we're doing to resect if there are solid tumors and then treatments have improved drastically over the last fifty years um long-term survival rates for cancer is now somewhere around I think it exceeds 85 now depending on the type of cancer you have that number might be a little bit different. But overall we expect in the United States 4 out of 5 children to survive their cancer that means 1 and 5 is not so depending on how you look at this statistic. It could be good or bad but it's it's inspiring or promising that we are getting to the point where I mean we were looking at leukemia in the sixties, the survival rate was 20%. And so you know to be up to eighty ninety percent for that group is fantastic. Um, but I care a lot about these survivors because um, we I guess. I guess what I want to say is that cure is not enough anymore. So ah, originally we were working for a cure and now that's not enough now we can't just try to save lives. We have to improve the quality of life of survivors. We want to make sure that they um have the ability to lead meaningful lives and feel good about the things that they can do even though that they're they're likely to participate in life with deficits in some form or fashion and so I think because you know I think it's really important that in order for us to meet the needs of this growing. Um, group of survivors. We really have to look at what our role is like in that um in that group just as a rehabilitation field so speech language pathologists, occupational therapists, physical therapists, audiologists kind of across the board. We do have a really important role in the care of these kids.

07:50.22
Leigh Ann Porter
I Really appreciate how you're framing this talk in helping us not just look at like, ok so individuals are now surviving childhood cancer at a higher rate. So like Yay! We won! We're Winning. We're on the journey of winning. And that's all like you're looking at how to go from surviving to thriving for this patient population and acknowledging that even though they've survived the cancer that doesn't mean it hasn't had (as our title indicates) a lasting effect on them in some form or fashion. So What does that look like specifically for SLps? Where do we come into play?

08:26.89
Kristin Szymanek

Yes, so let's talk a little bit about long-term effects and late effects. So when we think of these different side effects of cancer and its treatment. So patients can have problems that are caused by the cancer itself. So maybe it's the tumor burden that is causing issues. They can have side effects from the types of treatment that we used to um combat the cancer so that might be the surgery to remove the tumor. It could be radiation or chemotherapy or bone marrow transplant. Could be a combination of a lot of different treatments that can cause some of these long-term problems so we've got long-term effects which are these side effects that might persist for weeks or months or years after the completion of treatment and then we've got these sneaky little things called late effects. And so these are the things these are the issues that don't arise until long after treatment is complete. They might not even be evident. You know for a couple years or decades after treatment has been completed and so sometimes I think providers forget that it could be tied to the medical history of having childhood cancer. Um, often these long-term effects these late effects depend on the type and the location of the cancer and so some of these examples of long-term or late effects are things like cardiac toxicity or pulmonary fibrosis or um, infertility, growth hormone deficiencies development of other cancers and in childhood Cancer. There's a really unique idea about accelerated aging so that these kids they appear to be aging more quickly. Um, than their healthy same age peers. Um, and so.

10:19.83
Leigh Ann Porter
Okay, you just blew my mind with that Kristin. We're just going to have to sit and let that marinate for a hot minute. Are we talking like… no, Benjamin button was reverse aging. I'm like what's happening? Like, seriously, tell more about this.

10:33.47
Kristin Szymanek
Yeah, so accelerated aging is really interesting and we've done a lot of work in the research behind this because we were noticing that children were appearing like Geriatric adults. So the way that their posture like that kind of like slumped over posture, short stature. Of course our children don't always grow hair back. So sometimes even like just what they looked like kind of gave them this older look. But then we're also seeing it with neurocognition where they're um they’re starting to look into you know earlier onset dementia for childhood cancer survivors and things like this. Yeah, it's really really interesting. Um, yeah, so not only accelerated aging of like the body and like bone density and those types of things but even like accelerated cognitive aging. There's some really great research out there about it I can I can put it in the show notes for everybody interested.

11:26.73
Leigh Ann Porter
Um, Kristin you need to come back and just have a talk about this right here because I am like all over the place right now. Like I can't focus. Just like how have I not heard about this before? This is really intense. So at what point of their life are they seeing this accelerated aging? Like a few months after they do chemotherapy, surgery? Is this like a few years later? Like are they

adults when they see this? Or like they're still children? Like preteens, like before puberty they're seeing this accelerated aging like coming in?

12:05.15
Kristin Szymanek
So yeah, so some patients and I can't speak to the cognitive stuff as well. So cognitive late effects are usually evident within well it kind of depends on the age of the patient but within a few years of completion of treatment. So I'll give you a good example for cognitive late effects. So if you have a preschooler who comes to the hospital and is treated for a brain tumor depending on their age they might receive radiation. They might not be old enough. We usually delay radiation until they're about 3 years of age just because we don't want to radiate the developing brain but they will go through chemotherapy. Um. And if they go through chemotherapy and then potentially go back and have some radiation. Whatever the treatment regimen may be. We've noticed that okay they seem to be doing okay, when they're 3, 4 but they get to kindergarten and they're having trouble with attention, with working memory, with processing speed, with executive functioning. And it's because it was this delayed late effect of we weren't this wasn't apparent earlier on because the academic demand for our three year old is nowhere near the academic demand of a kindergartner. So. It's it's just this really interesting kind of like delayed onset of these issues that we're seeing um. That's from a cognitive standpoint. So Your question was about accelerated aging and when we might see it for patients. So um, the physical accelerated aging isn't as much of my wheelhouse but we do have some researchers here who have done a lot of work on it and you will actually see kids who are on Therapy. You just look at him walking down the hall and you're like man he looks like an old man and like the stopp and recover to try to pick something off the floor looks really difficult and so you start to like they just look like these old little men and women sometimes just because they're having so much trouble with the basics of movement and mobility. It's very interesting but.

13:59.34
Leigh Ann Porter
Yeah I have a lot more questions, but I'm going to not ask them because that was not the point of today's gathering um oh wow. Okay, so yeah, oh gosh I just have to stop talking. Okay so on to you.

14:06.21
Kristin Szymanek
Um, yeah, what, what I was go say I can circle it back to some of the kind of more speech therapy focused long-term effects and late effects that we might see. So one thing I did want to kind of point out is that. Um, childhood cancer survivors I think are like eight times more likely to have chronic illnesses than their healthy same age peers or siblings and so and in addition to being more likely to have these chronic health conditions, they're also more likely to have multiple health conditions. So I think I can't remember where I read this but it was something like childhood cancer survivors experience on average around 15 or 17 different chronic health conditions whereas the general population of the same age experience like 3 so. It's just it's

wildly different that they're experiencing so many more of these health conditions in life that they're now having to deal with that are a result of cancer treatment or cancer diagnosis when they're younger.

15:18.90
Leigh Ann Porter
Yeah, I'm like how how many of those diagnoses might be iatrogenic? Did I say that word right?

15:23.10
Kristin Szymanek
Yeah, iatrogenic. Yeah, so so so some yes and then some it's straight up treatment related so and there's been a lot of research too on kind of what to expect? So a really good example for a speech language pathologist is. Um, hearing loss is a huge side effect of childhood cancer treatment. We have nailed down the chemotherapies that are ototoxic and it is very very much on the radar of the medical team to monitor hearing because we know that the likelihood of a patient experiencing hearing loss if they're given high doses of certain chemotherapies is just really high so hearing loss is a big one. We fit a lot of kids with hearing aids. Um, we have a lot of patients who are eventually cochlear implant candidates. Um, but the tricky thing about that is if it's a brain tumor patient. We might have to delay their cochlear implantation because of the artifact of the internal processor during MRIs and these kids get so many serial like serial imaging is a big thing. Um, and so we can't risk not being able to see tumor growth, recurrence, progression et cetera because we wanted them to hear better. But we know that them being able to hear better would greatly impact their quality of life. So it's this really tough kind of tug of How do we proceed, but a lot of times the the MRI wins and then we'll we'll continue to talk to the medical team and by we I mean our fabulous audiologists here at my facility will continue to advocate for those patients until they get to a point where they're comfortable saying. Okay we are willing to, um, deal with a little bit of artifact. We feel good about where they are in terms of their brain tumor and we're going to go ahead and and move forward with the cochlear implant for that patient so hearing loss is a huge late effect. Um. I think another ah ah like a little bit more of a shorter term late effect that might resonate with some people are feeding and swallowing problems. A lot of times feeding and swallowing problems occur as a result of the surgery or chemotherapy, radiation those types of things. But one thing that we're seeing is that these patients often have feeding tube dependency and so you know a patient might go back to their home community and be finished with cancer treatment but they are dependent on a feeding tube and are not, you know, eating orally or are not meeting their nutritional needs by mouth alone and so they need that supplemental nutrition and so that's an area that people can be aware of you know if you if you receive a childhood cancer patient who has finished their treatment looking at their feeding and swallowing skills. Um. I think some of the other ones that are big for this group. Let's see. Um, we talked about neurocognition so problems with attention, working memory, processing speed, executive function even some of the visual spatial or visual motor skills can be difficult. Um. There's like osteoradionecrosis of the teeth. So. There can be some dental issues. There can be patients might need extractions or implants. Um trismus is a big one if you've had radiation to the head and neck. You can have some jaw issues same thing with like fibrosis. Um, in that area that can cause you know narrowing of the esophagus and

actually that one's that's a big one now that we see from patients who were who underwent radiation like twenty years ago, we're starting to see some of those kids with some because radiation back then just wasn't as great as it is now and so we're seeing a lot of of what some people will call Woody neck which is just some really fibrotic tissue some narrowing in the esophagus and they'll they'll say I don't know what's happening. But. I'm choking all of the time and I wasn't choking before um so some of those effects um a lot of my kids will have issues with dysarthria long-term um you know so issues with pitch and volume and breath support and articulation and intelligibility. Um, Dysgeusia is a big one so chemotherapy can cause issues or cause altered taste perception and some patients have a really really hard time with it and just don't really ever get over it. They just really never have that motivation to eat or have that same enjoyment as they had before and I think a lot of these things these different late effects and and long-term effects really can impact life participation and they can impact social success. And even academic achievement and career attainment and so I think that's I'm just so passionate about it because I know that you know these are areas that can be really impactful um or can really impair quality of life for for our survivors.

20:50.78
Leigh Ann Porter
That is so good and so important. I'm loving all of this Kristin. This is such a delight for me. One of the things that I love so much about your talk is that, Um, you're seeing them at one part of their care and you're recognizing that this is something that's going to be with them at different stages of their life. Um, when they won't necessarily like come to your facility for care like when they go on and see people who work at, you know, outpatient or maybe they because they have so many comorbidities they're going to be seen at adult hospitals in the future and so it is this continuity of care that we all need to be on the same page and know that what happened back then like exactly how it's impacting. Um, that's so fascinating.

21:35.18
Kristin Szymanek
And it's such, to me, it’s such a good lesson and there's always something new to learn in our field like this is my niche and like this is what I do all day long. But if it weren't. And you know I worked in the school or I worked in an outpatient clinic or whatever and you know one of these patients could end up on my caseload like I recognize that that would take work for people to then just pick that patient up and keep moving forward with their with their treatment. Um, and so. You know I hope people consider this an opportunity to continue to learn more about our field. But I think like you were saying. It's such a ah good lesson in coordination of care and how we support continuity of care and for us that might mean, you know, sometimes I will call the facility if I know where they're going to say hey this is what's coming your way and I'm here if you have any questions if you feel good about It. You're doing great but just let me know you know what I can do to help. When I think about childhood cancer and and survivors I also think about you know the impact of treatment now but also in the future and it kind of gets my wheels spinning about even the things we do now as speech pathologists. What is that going to look like in the future and what are we going to learn from that and how is that going to kind of guide

our clinical practice moving forward which you know I could go down a huge rabbit hole with that one? Um, So yeah, yeah.

23:10.25
Leigh Ann Porter
That sounds awesome. That sounds right at my alley. I Love thinking about the future as I look at how our practice patterns are shifting and changing and how we're growing as a field and how our focus is always evolving on what that looks like.

23:24.58
Kristin Szymanek
Okay.

23:28.50
Leigh Ann Porter
That gets me excited about the future too. So like I love that. Like, looking back, looking now, and looking forward and shaping the future. Like that's very exciting.

23:34.74
Kristin Szymanek
Yeah, Well I think some of the things in the field that have been exciting to me more recently and I'm learning more about myself are things like patient-reported outcome measures right? So How do we use these to really get the patient involved in their care. But then I think it I think it serves a dual purpose in that it gives us information that's helpful to us. But it also gets them thinking about what's going on and how they feel and I think, I personally believe that when they participate in some of those measures, they're better able to identify when something's different or when something doesn't feel right or hey maybe I should call the SLPS or call the doctor and say this is what's going on and so sometimes I think we get better referrals when they know what they're supposed to be thinking about and then the other thing is in, Um, childhood cancer. There's a lot of emphasis on surveillance models and so we are trying to understand how we can, like, anticipate late effects and long-term outcomes and so these surveillance programs are aimed at creating kind of like these cancer treatment summaries that can then follow the patient to their next facility or they might develop a survivorship care plan that can, you know, give the medical team just some ideas of hey this is what you might expect in the next five, ten, fifteen years. Um I know several organizations like children's oncology group and other groups have been working on clinical guidelines for survivors of childhood cancer which can really kind of pave the way of this is what we need to do um and then there's this new idea of risk. Um. Risk prediction modeling which can basically take scientific evidence and turn it into risk for an individual survivor so they're actually getting down to really individualized looks at okay, not just for this population. This is what we expect and what this might look like but for you specifically. You had these treatments and this is what we would expect your path forward to look for and these are the types of people that you want to have involved in your care to best support you moving forward.

26:00.32
Leigh Ann Porter
That's good. That's really good.

26:02.88
Kristin Szymanek
It's just yeah, it's just really Interesting. Um I think Chronic Health conditions. You know we all dabble in it a little bit as speech pathologists like that's that's part of what we do and so it makes sense that childhood cancer survivors would also experience them. Um. But yeah, just an interesting look at ah at a small group um a small group of people that you know honestly I like to think about it as I hope I don't have a job one day I Hope that means that childhood cancer doesn't exist so you can't employ me anymore as ah as a oncology SLP. But in the meantime if I am sending more of these survivors out in the world and more of you, the listeners, are seeing them in your clinics, in your schools than we're doing our job and we're headed in the right direction and that's really exciting like I want you to be able to see these patients and know some of the joy that I know working with them.

26:59.10
Leigh Ann Porter
That's awesome. I Love it so much. This is great. Um, at risk of opening a can of worms. Ah I'm going to do it anyway because I'm a glutton for punishment. Okay, we are circling back to that aging situation because I have a question.

27:12.34
Kristin Szymanek
Yes.

27:15.30
Leigh Ann Porter
How much does that mirror like a developmental delay because it is interrupting as they're going through treatment as they're dealing with this life threatening condition? It's taking them out of their home. It's taking them away from those experiences that help them grow and develop and learn. It is interrupting that cycle. So how much of that premature aging is related or also just ah, a delayed development? Like, talk to me about that. I'm sure these researchers have had to look at that and isolate which is which. What's playing into what.

27:50.67
Kristin Szymanek
So I can't give you a firm answer because again this is not my wheelhouse but I can give you maybe some ideas or how I think about it. So when I'm thinking about smaller children like toddlers going through cancer treatment a lot of them like you were saying, things are disrupted and they just don't learn the skill so they have problems with skill acquisition and so as they learn the skill, it might look a little bit different because of you know, maybe they have ataxia or maybe they just laid in a hospital bed for a long time because they felt so sick and so that just

delayed their ability to walk or whatever the case may be whereas some of these older kids who already had the skill but are now showing either regression and then they're trying to recover that skill. I think that group that we're seeing the accelerated aging in a little bit more now again, this is coming out of my SLP brain, so I would love to actually circle back with you and kind of follow up on this or at least share some of the the research I'll have to dig into that again. But I think that's kind of the group that they're really focusing on are these, these older patients who have already acquired the skills and what it looks like moving forward for them. So kids who are already walking and were quote unquote typical 8 year olds or whatever the case may be and now they've got this more hunched over posture and you know they have like an interesting gait that you see in like older gentlemen those types of things whereas the toddlers are just, like you're saying that, like delayed development, that delayed skill acquisition. It's all very very interesting though.

29:31.59
Leigh Ann Porter
Ah, yeah, isn't it. The wheels are turning. Thank you for like going through that again with me Kristin. That was awesome. Um, ok, well anything else that we need to cover? What other bullet points do we need to touch on about um, the lasting effects of childhood cancer?

29:51.83
Kristin Szymanek
Gosh I mean without going on for like four more hours um I think we hit a lot of it, you know, in a short amount of time and I hope people are able to see um that you know we we really have to shift our mindset from cure to quality. I think that's kind of my big takeaway is we can help people. We're not here to fix people. We're here to help them, um, live meaningful lives and participate in the activities that they want to participate in and achieve the goals that they have for themselves not necessarily the goals that I might have for them. Um, and it's a really fun group to do it with um I work with a very resilient patient population and so it's a really exciting um, exciting thing to be a part of.

30:50.16
Leigh Ann Porter
That's so cool. I really appreciate how you touched on that we don't fix people because that's also how I approach my work with adults. It's like I'm not here to fix anything, like I'm a guide, I provide tools. And um, I really also like how you talked about moving from like cure to quality like it's not enough, I mean it is enough to preserve life. That is an excellent goal to have and to maintain. But once we have that life. What about the quality? What are we leaving people with after their treatments and how can we better provide for that quality of life? That engagement, that participation? That's really awesome. Thank you so much Kristin!

31:29.31
Kristin Szymanek
Yeah, thank you for having me. This was fun.

31:36.85
Leigh Ann Porter
Oh ok, so before we part ways, Um, tell me a little bit about the resources that you've provided for the show notes and how people can get in touch with you and learn more about these awesome things that you've talked about today.

31:43.96
Kristin Szymanek
Yes, so I included several articles about childhood cancer in general. So if anybody's interested in just learning a little bit more about the role the role of Rehab Professionals in this group as well as some articles about, um, late effects that relate to the SLP. Um I believe I added a couple of websites one of which is the Together website. That's a really nice, um, informational website that was really built for caregivers of patients with childhood cancer. However, I think it does a really nice job of providing like very easy to digest information just about childhood cancer in general you know all sorts of diagnoses, all sorts of treatment modalities, what people can expect, what it looks like to have a speech pathologist involved in your care. All of those types of things. And then if people ever want to get in touch with me I am on Instagram I'm at pedoncslp it's @ped.onc.SLP and I like to do a little bit of Pediatric Oncology Education, quizzes and chart reviews, some fun stuff like that. It's it's a nice little creative outlet for me so people are more than welcome to find me there and shoot me a Dm. Yeah.

33:07.60
Leigh Ann Porter
So all right! Well wonderful and I think that's that's it for us then. So, I'm so glad that our listeners have joined us today and learned or refreshed their knowledge in this area. I was about to be sarcastic, be like the other five SLPs who specialize in pediatric onc. Like, I know there's more than five, but you you guys are a very specialized, very niche group and I can't imagine that there are very many of you. But I'm so glad you exist and the work that you do. So, Thanks for listening and joining us today and then I hope what you've learned here helps you nourish so that your practice flourishes and that you all go out there and be awesome.

33:47.83
Kristin Szymanek
Thanks so much.